THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

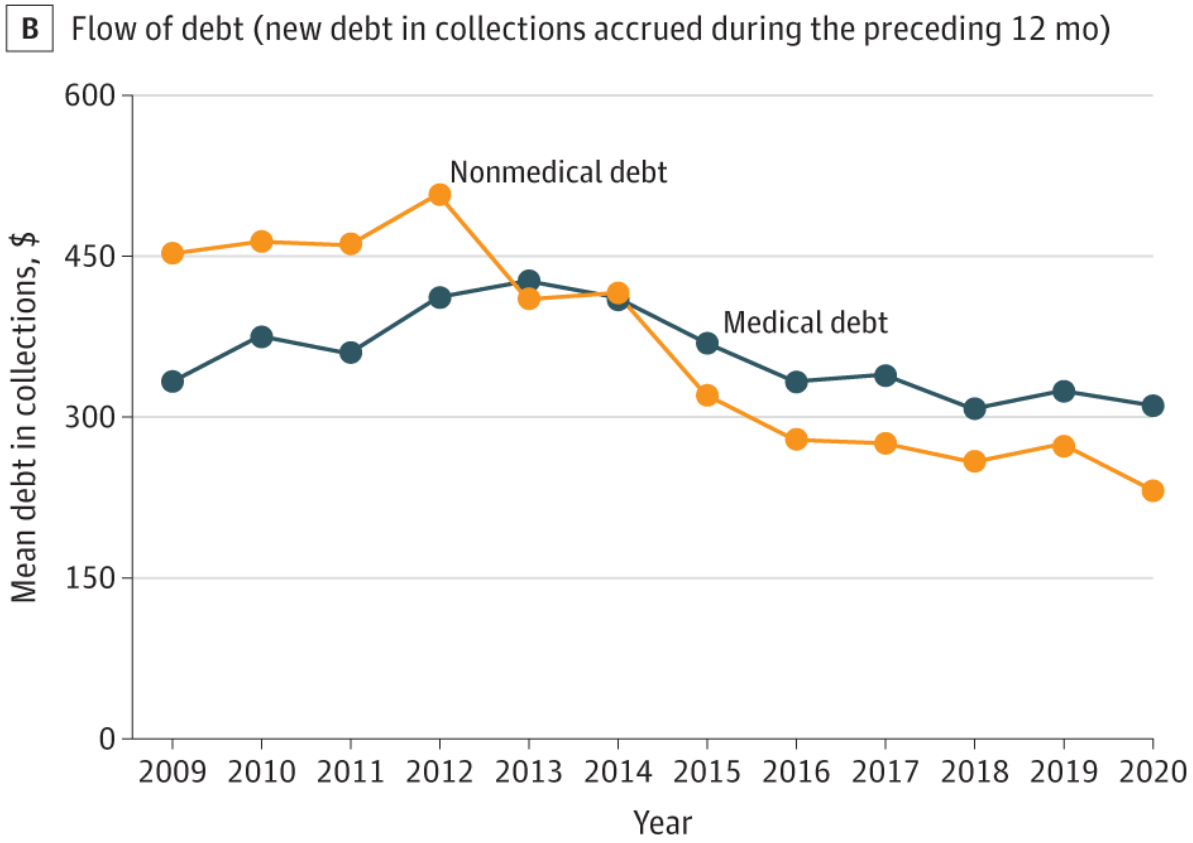
Cured into Destitution

FINANCIAL TOXICITY & BREAST CANCER CARE

@anaeze_offodile

AUGUST 22ND, 2022

17.8% of Americans report medical debt



Total medical debt in collections = $140 billion

JAMA 2021; 321(3): 250-56

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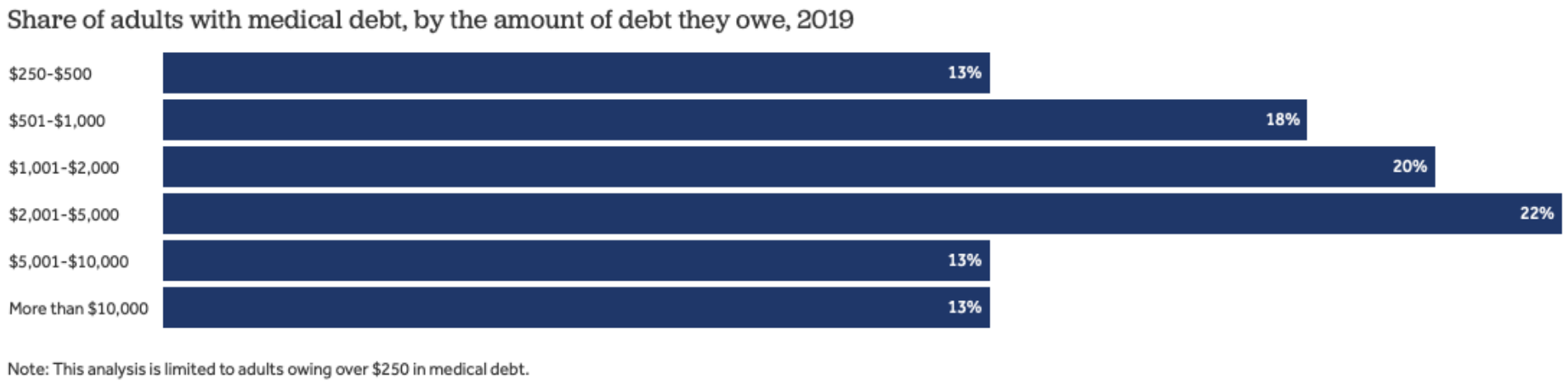
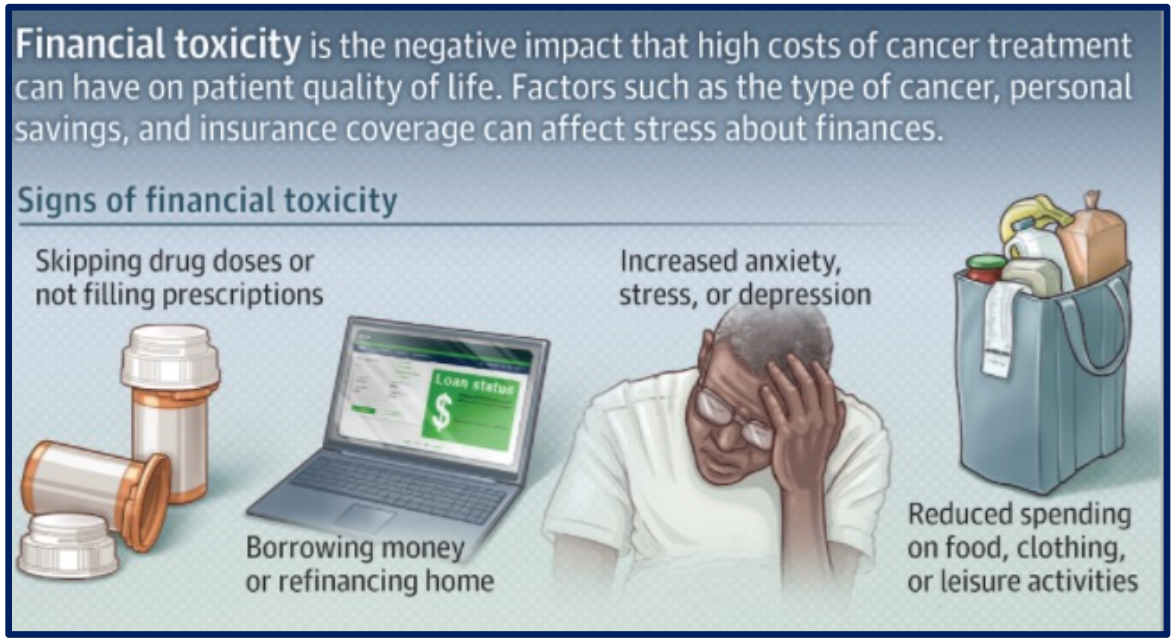
Most people report significant medical debt



Peterson-KFF Health System Tracker 2022

Definition



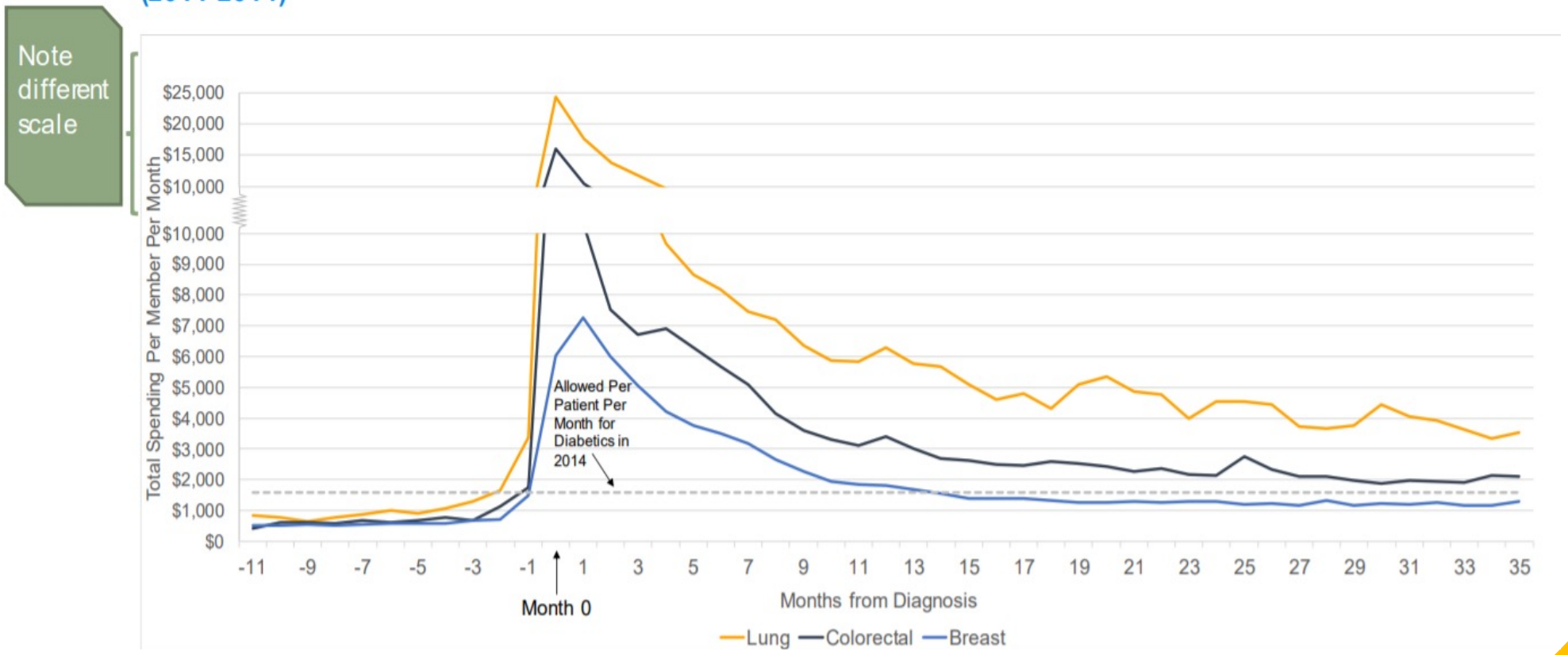
Cancer is 2nd most expensive chronic condition per capita in the US

- Advancements in diagnosis/treatment, over-treatment, ↑ cost-sharing
- 48-73% of survivors report financial hardship
- Worse QoL, bankruptcy, treatment non-adherence & symptom burden

Jour of Surg Onc. 2019; 120(1): 85-92. & JAMA Onc March 2022

Cancer care is abrupt and expensive

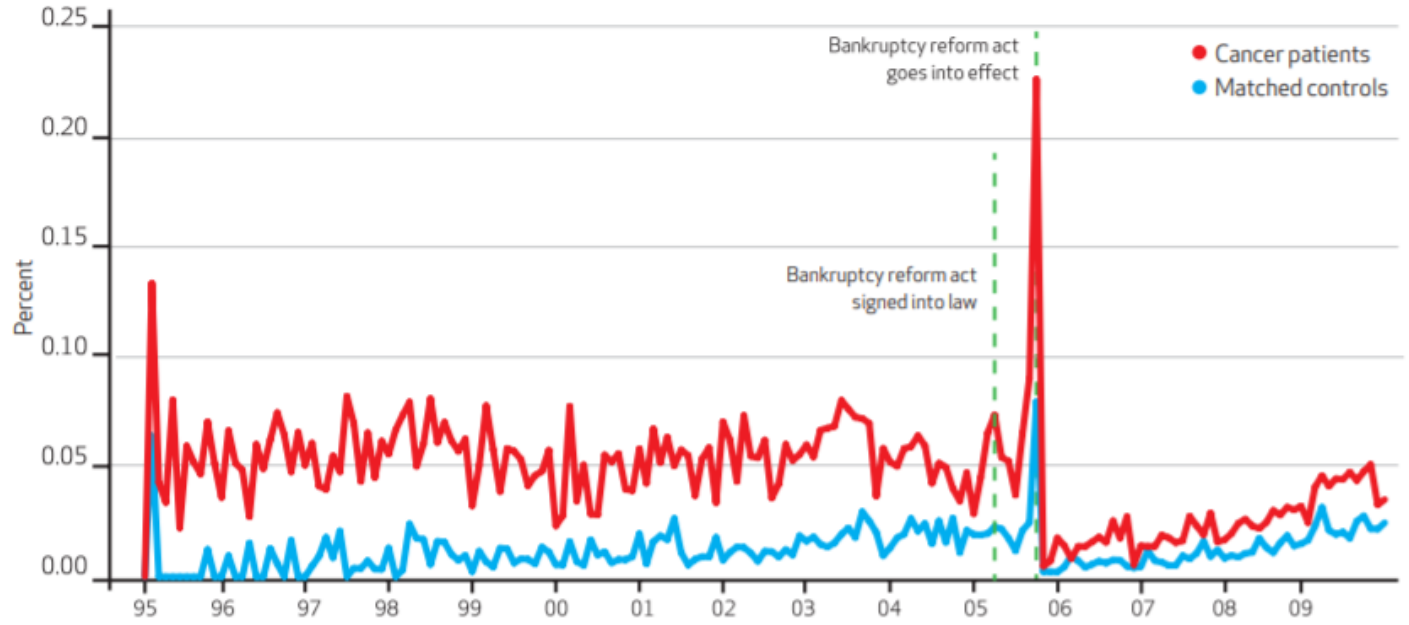
FIGURE 1: AVERAGE MONTHLY HEALTHCARE SPENDING BEFORE AND AFTER DIAGNOSIS, BY CANCER TYPE (2011-2014)[a]



Analysis by Milliman Group

Cancer patients are at greater risk for bankruptcy

Monthly Rate Of Bankruptcies For Cancer Patients And Matched Group Without Cancer, Western Washington State, 1995–2009



SOURCE Authors' analysis. **NOTE** People in the group without cancer were matched to cancer patients by age, sex, and ZIP code of residence.

Health Affairs. 2013; 32(6): 1143-52

Bankruptcy = Independent RF for ↑ mortality

Table 3. Bankruptcy Impact on All-Cause Mortality in the Propensity Score Matched Sample

Cancer Type	No. at Risk	No. of Deaths	HR	95% CI	*P*
Overall	17,021	2,026	1.79	1.64 to 1.96	< .001
Breast	3,788	280	1.48	1.15 to 1.91	.003
Lung	958	350	1.55	1.22 to 1.98	< .001
Melanoma	1,197	51	1.50	0.83 to 2.72	.179
Thyroid	952	23	1.71	0.69 to 4.27	.249
Prostate	2,365	214	2.07	1.56 to 2.74	< .001
Leukemia/lymphoma	1,792	254	1.22	0.93 to 1.61	.146
Uterine	739	42	1.09	0.55 to 2.16	.795
Colorectal	1,430	217	2.47	1.85 to 3.31	< .001
Other	3,800	595	1.49	1.25 to 1.78	< .001

Abbreviation: HR, hazard ratio.

N = 7,570 total patients. Matched pairs of adult cancer patients with a bankruptcy filing and those who did not. All in the Greater Washington area between 1995-2009

Journ of Clin Oncol. 2016; 34(9): 980-86

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Three domains of financial toxicity (FT)

Material Conditions

Example concepts within this domain:

- Out-of-pocket expenses
- Missed work
- Reduced/lost income
- Medical debt/bankruptcy

Psychological Response

Example concepts within this domain:

- Feeling of distress due to costs of cancer care
- Concern about wages/income meeting expenses related to costs of cancer care

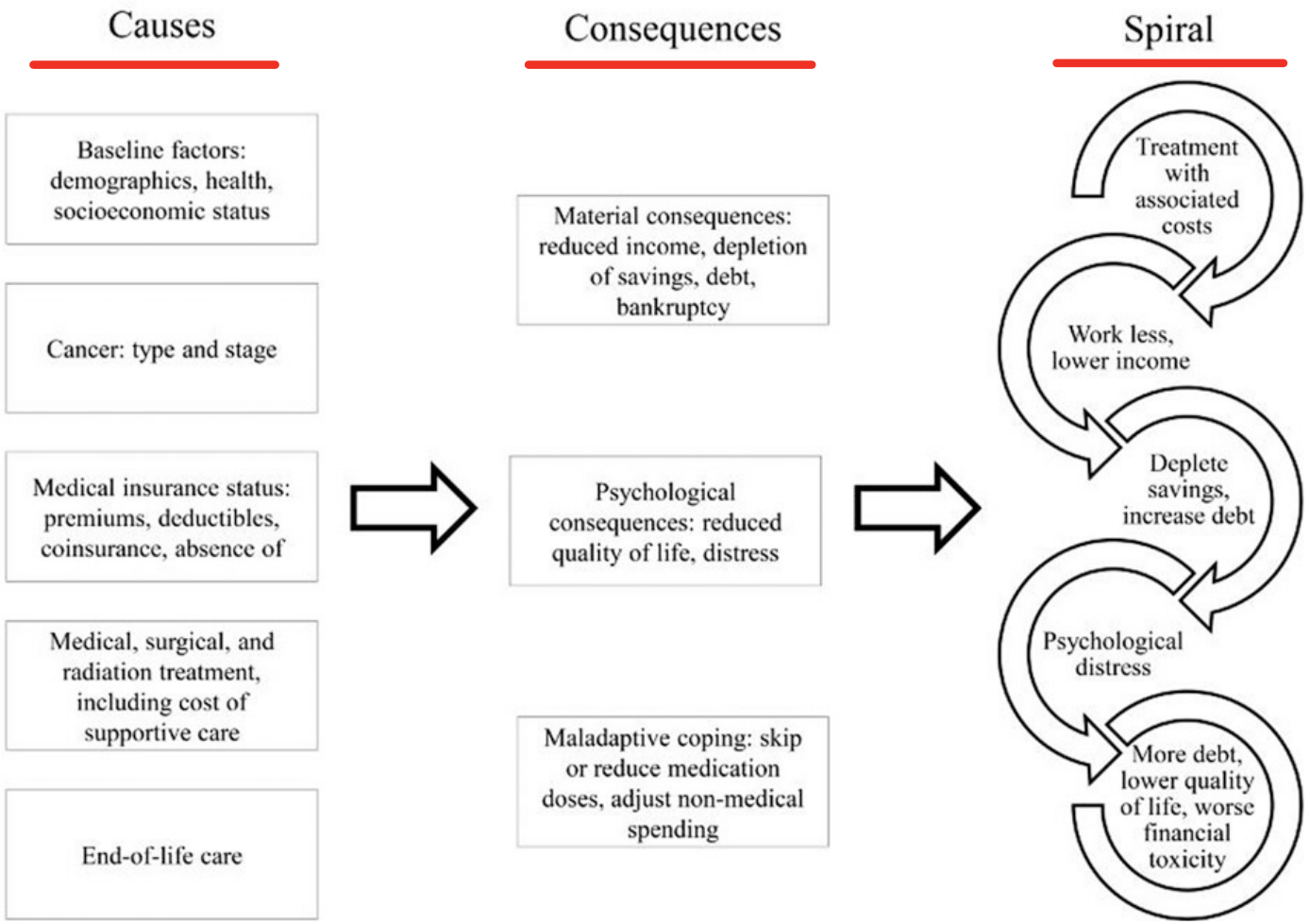
Coping Behaviors

Example concepts within this domain:

- Took less or skipped medication
- Delayed or missed physician visit

JNCI. 2017; 109(2). doi: 10.1093/jnci/djw205

Conceptual framework

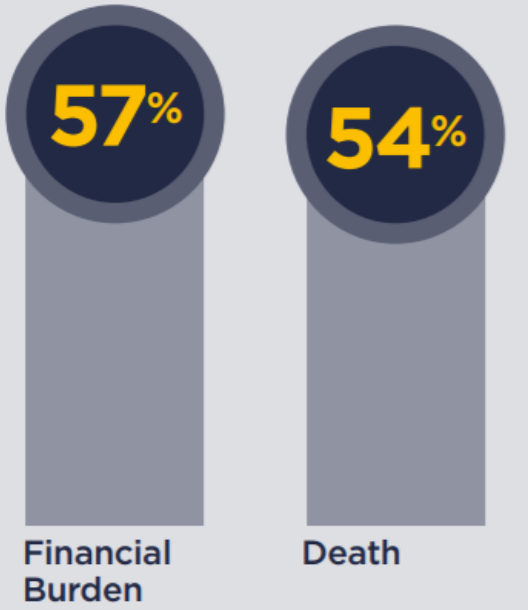


Journal of Surg Oncol. 2019; 120(1): 85-92

ASCO 2018 National Cancer Opinion Survey

Cancer's Financial and Access Challenges

Just as many Americans are worried about **cancer's financial impact as about dying of cancer**



61% of **caregivers** say they or a loved one have taken at least one onerous step to **pay for cancer care** including:

- 35% dipped into **savings account**
- 23% worked **extra hours**
- 14% postponed **retirement**
- 13% took on an **additional job**

43% of **cancer patients** experienced barriers to accessing the best possible care due to **health insurance coverage**

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Growing attention in lay press as well

LIVING WITH CANCER

The Financial Toxicity of Illness

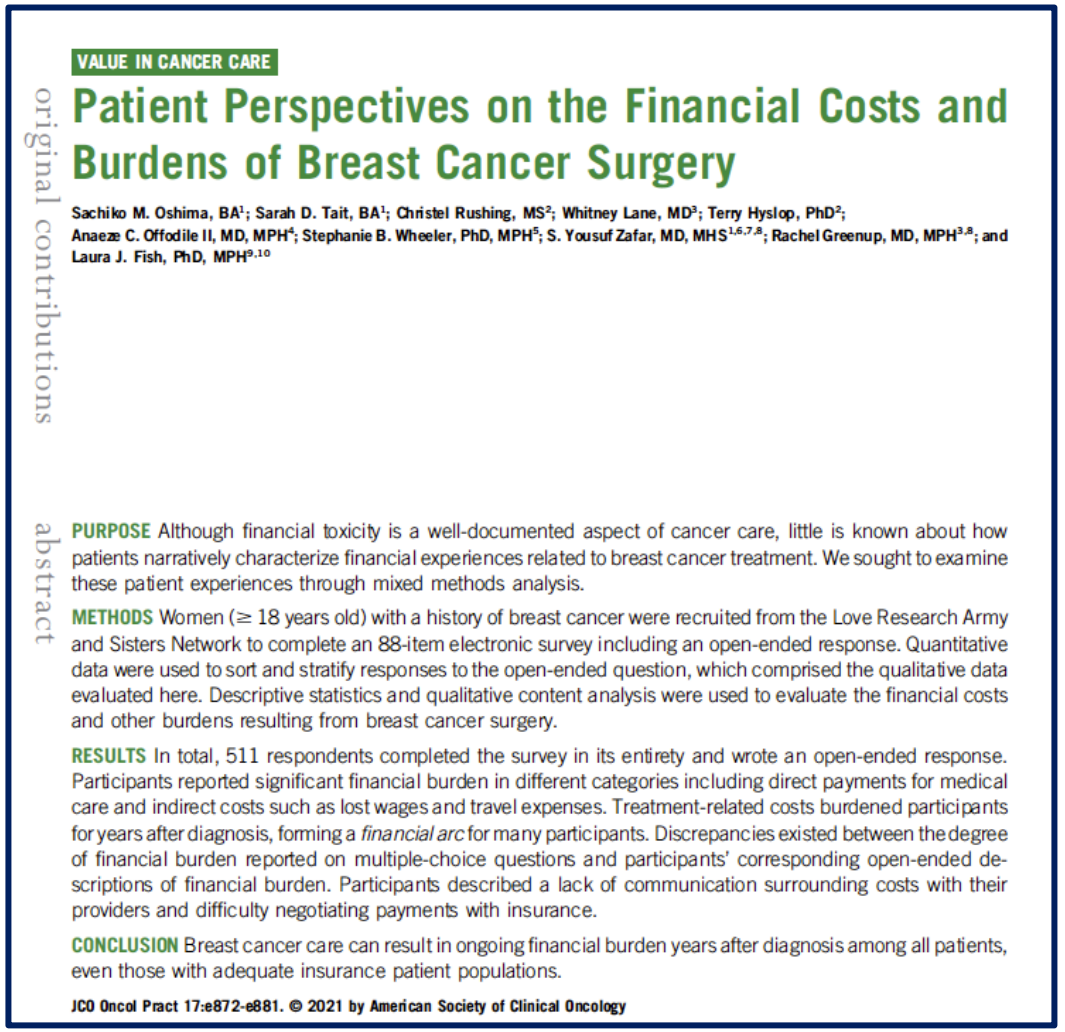
While medicine transforms cancer into a chronic disease with which patients can live for an extended period of time, financial toxicity threatens to turn chronic, too.

Jaime Jacob

By Susan Gubar

NY Times. Feb 2019

How do patients characterize FT?



VALUE IN CANCER CARE

Patient Perspectives on the Financial Costs and Burdens of Breast Cancer Surgery

Sachiko M. Oshima, BA[1]; Sarah D. Tait, BA[1]; Christel Rushing, MS[2]; Whitney Lane, MD[3]; Terry Hyslop, PhD[2]; Anaeze C. Offodile II, MD, MPH[4]; Stephanie B. Wheeler, PhD, MPH[5]; S. Yousuf Zafar, MD, MHS[1,6,7,8]; Rachel Greenup, MD, MPH[3,8]; and Laura J. Fish, PhD, MPH[9,10]

original contributions

abstract

PURPOSE Although financial toxicity is a well-documented aspect of cancer care, little is known about how patients narratively characterize financial experiences related to breast cancer treatment. We sought to examine these patient experiences through mixed methods analysis.

METHODS Women (≥ 18 years old) with a history of breast cancer were recruited from the Love Research Army and Sisters Network to complete an 88-item electronic survey including an open-ended response. Quantitative data were used to sort and stratify responses to the open-ended question, which comprised the qualitative data evaluated here. Descriptive statistics and qualitative content analysis were used to evaluate the financial costs and other burdens resulting from breast cancer surgery.

RESULTS In total, 511 respondents completed the survey in its entirety and wrote an open-ended response. Participants reported significant financial burden in different categories including direct payments for medical care and indirect costs such as lost wages and travel expenses. Treatment-related costs burdened participants for years after diagnosis, forming a *financial arc* for many participants. Discrepancies existed between the degree of financial burden reported on multiple-choice questions and participants' corresponding open-ended descriptions of financial burden. Participants described a lack of communication surrounding costs with their providers and difficulty negotiating payments with insurance.

CONCLUSION Breast cancer care can result in ongoing financial burden years after diagnosis among all patients, even those with adequate insurance patient populations.

JCO Oncol Pract 17:e872-e881.

JCO Oncol Pract. 2021; 17(6): e872-881

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Key themes representing patient perspectives

"For me, the financial aspect of my treatment was incredibly anxiety provoking and subsequently, guilt ridden. There was no question that I was going to undergo treatment, but we had to use savings to cover all of the costs, ask our families for support…" (Limited resources)

"I heard rumors at work that I was often passed over for promotions, because they feared that if I got cancer again, they would have to pay me more if I had to go on medical disability. It took me 10 years to finally get a promotion that I had deserved…" (Career disruption)

"Living 100 miles from Dr's and treatments – traveling was my biggest hardship" (Indirect costs)

JCO Oncol Pract. 2021; 17(6): e872-881

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JCO Oncol Pract. 2021; 17(6): e872-881

How do we measure FT?

Original Article

Measuring Financial Toxicity as a Clinically Relevant Patient-Reported Outcome: The Validation of the COmprehensive Score for financial Toxicity (COST)

Jonas A. de Souza, MD, MBA[1]; Bonnie J. Yap, MS[1]; Kristen Wroblewski, MS[2]; Victoria Blinder, MD, MSc[3]; Fabiana S. Araújo, PhD[4]; Fay J. Hlubocky, PhD[1]; Lauren H. Nicholas, PhD[5]; Jeremy M. O'Connor, MD[1]; Bruce Brockstein, MD[6]; Mark J. Ratain, MD[1]; Christopher K. Daugherty, MD[1]; and David Cella, PhD[7]

BACKGROUND: Cancer and its treatment lead to increased financial distress for patients. To the authors' knowledge, to date, no standardized patient-reported outcome measure has been validated to assess this distress. **METHODS:** Patients with AJCC Stage IV solid tumors receiving chemotherapy for at least 2 months were recruited. Financial toxicity was measured by the COmprehensive Score for financial Toxicity (COST) measure. The authors collected data regarding patient characteristics, clinical trial participation, health care use, willingness to discuss costs, psychological distress (Brief Profile of Mood States [POMS]), and health-related quality of life (HRQOL) as measured by the Functional Assessment of Cancer Therapy: General (FACT-G) and the European Organization for Research and Treatment of Cancer (EORTC) QOL questionnaires. Test-retest reliability, internal consistency, and validity of the COST measure were assessed using standard-scale construction techniques. Associations between the resulting factors and other variables were assessed using multivariable analyses. **RESULTS:** A total of 375 patients with advanced cancer were approached, 233 of whom (62.1%) agreed to participate. The COST measure demonstrated high internal consistency and test-retest reliability. Factor analyses revealed a coherent, single, latent variable (financial toxicity). COST values were found to be correlated with income (correlation coefficient [r] = 0.28; $P<.001$), psychosocial distress ($r = -0.26$; $P<.001$), and HRQOL, as measured by the FACT-G ($r = 0.42$; $P<.001$) and by the EORTC QOL instruments ($r = 0.33$; $P<.001$). Independent factors found to be associated with financial toxicity were race ($P = .04$), employment status ($P<.001$), income ($P = .003$), number of inpatient admissions ($P = .01$), and psychological distress ($P = .003$). Willingness to discuss costs was not found to be associated with the degree of financial distress ($P = .49$). **CONCLUSIONS:** The COST measure demonstrated reliability and validity in measuring financial toxicity. Its correlation with HRQOL indicates that financial toxicity is a clinically relevant patient-centered outcome. ***Cancer* 2017;123:476-84.** © *2016* The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of *American Cancer Society.* This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

KEYWORDS: cost of cancer, financial burden, financial toxicity, patient-reported outcome (PRO).

Cancer. 2017; 123: 476-84

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Who is at risk for FT

49% of cancer patients reported some form of FT

Risk profile: uninsured (2x), lower income, **young age**, unemployed, racial minority

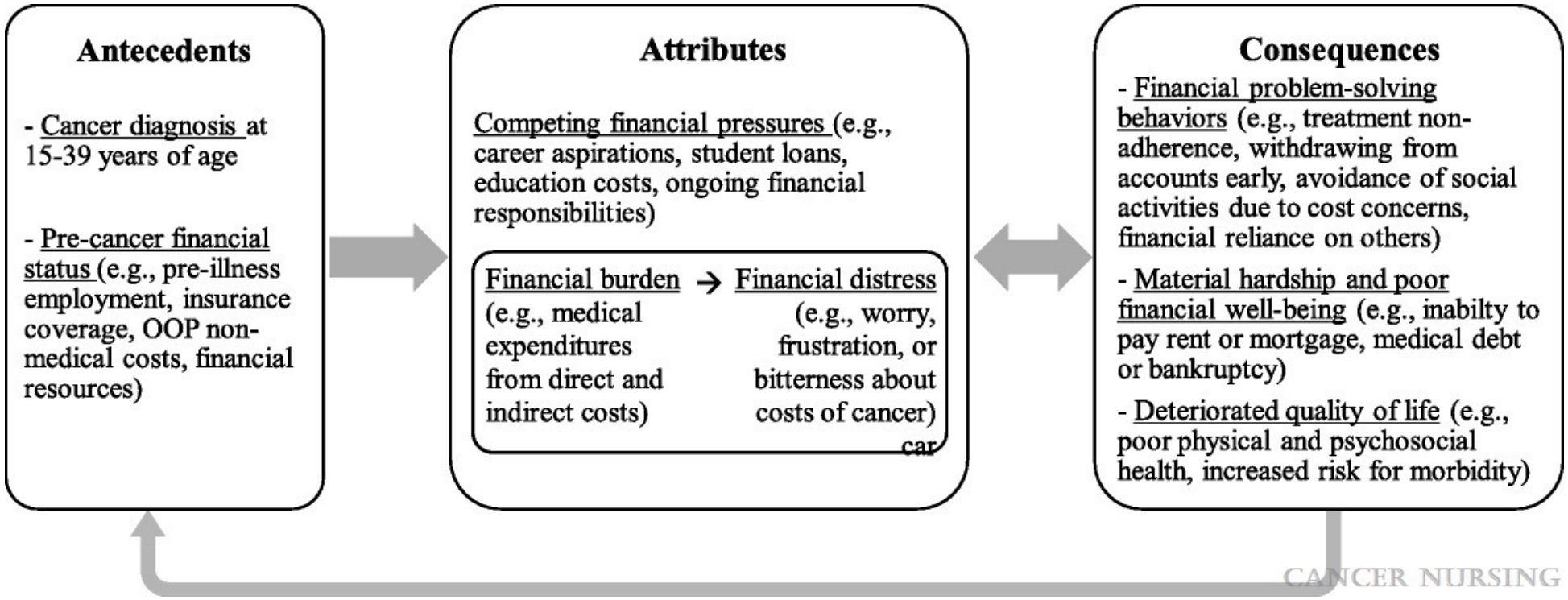
Timing: Early in treatment and no major

variation by disease site

Impact: Worse QoL & Rx non-adherence

J Natl Compr Canc Netw. 2019; 17(10): 1184-92

Contextualization of FT in AYA with cancer



Cancer Nursing. 2021; 44(6): e636-51

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COVID may exacerbate FT in AYA survivors

Original Article

Economic Distress, Financial Toxicity, and Medical Cost-Coping in Young Adult Cancer Survivors During the COVID-19 Pandemic: Findings From an Online Sample

Bridgette Thom, PhD [1]; Catherine Benedict, PhD [2]; Danielle N. Friedman, MD, MS [3]; Samantha E. Watson, MBA[4]; Michelle S. Zeitler, MPH[4]; and Fumiko Chino, MD [5]

BACKGROUND: Young adult (YA) cancer survivors are at risk for financial toxicity during and after cancer treatment. Financial toxicity has been associated with medical-related cost-coping behaviors such as skipping or delaying treatment. The coronavirus disease 2019 (COVID-19) pandemic has resulted in dire economic consequences that may worsen financial hardship among young survivors. **METHODS:** This was a cross-sectional survey; data collection occurred online. A convenience sample was recruited through YA cancer advocacy groups and social media. Negative economic events associated with the COVID-19 pandemic (eg, income loss, increased debt, and decreased job security) and medical-related cost-coping were documented. A validated measure assessed cancer-related financial toxicity. **RESULTS:** Participants (N = 212) had a mean age of 35.3 years at survey completion and a mean age of 27.4 years at diagnosis. Financial toxicity (mean, 14.0; SD, 9.33) was high. Two-thirds of the sample experienced at least 1 negative economic event during COVID-19, and 71% engaged in at least 1 medical cost-coping behavior. Cost-coping and pandemic-related negative economic events were significantly correlated with cancer-related financial toxicity. In multivariable analyses, pandemic-related negative economic events and financial toxicity were associated with cost-coping. **CONCLUSIONS:** Acute negative economic events associated with the COVID-19 pandemic may exacerbate cancer-related financial toxicity and overall financial hardship among YAs and lead to cost-coping behaviors that can compromise survivorship care and health outcomes. Multilevel, systematic interventions are needed to address the financial needs of YA survivors after the global pandemic. ***Cancer* 2021;127:4481-4491**. © *2021 American Cancer Society*.

KEYWORDS: coronavirus disease 2019 (COVID-19), cost-coping, financial toxicity, young adult, survivorship.

Cross-sectional survey (social media)

212 participants with a mean age of 27.4

High levels of financial toxicity (COST 14.0)

67% of patients reported at least 1 negative pandemic-related economic event (e.g., job loss)

71% in at least 1 coping behavior

Both strongly correlated with FT

Cancer. 2021; 127(23): 4481-91

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Why focus on breast cancer surgical patients?

Although effects are presumed to be similar, very limited data in a surgical oncology context i.e., causes and consequences

Breast cancer is expensive

- **highest among solid tumors ($20 billion in 2020) and has steepest trajectory**

Early-stage cancer is preference sensitive and a surgical disease

- BCT vs. mastectomy
- Contralateral prophylactic mastectomy

} equal outcomes but varying costs

Cost has been shown to influence treatment decisions

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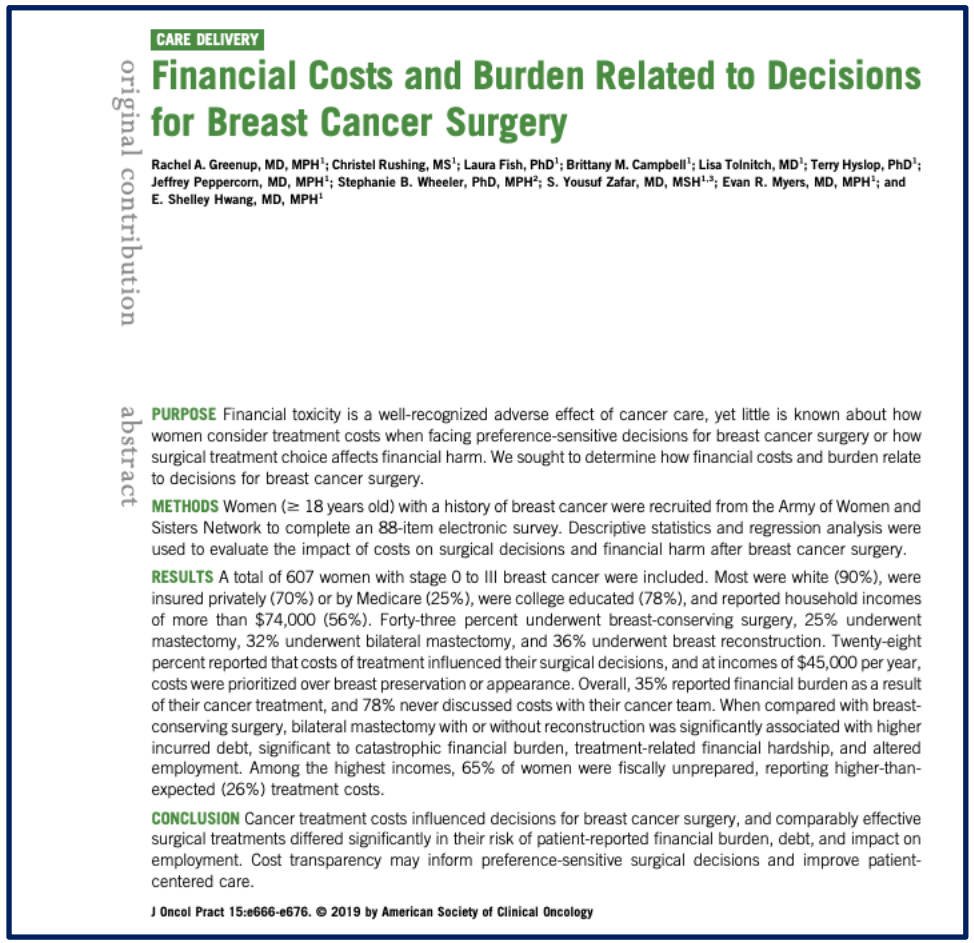
Impact of cost information in breast cancer surgery



original contribution

CARE DELIVERY

Financial Costs and Burden Related to Decisions for Breast Cancer Surgery

Rachel A. Greenup, MD, MPH[1]; Christel Rushing, MS[1]; Laura Fish, PhD[1]; Brittany M. Campbell[1]; Lisa Tolnitch, MD[1]; Terry Hyslop, PhD[1]; Jeffrey Peppercorn, MD, MPH[1]; Stephanie B. Wheeler, PhD, MPH[2]; S. Yousuf Zafar, MD, MSH[1,3]; Evan R. Myers, MD, MPH[1]; and E. Shelley Hwang, MD, MPH[1]

abstract

PURPOSE Financial toxicity is a well-recognized adverse effect of cancer care, yet little is known about how women consider treatment costs when facing preference-sensitive decisions for breast cancer surgery or how surgical treatment choice affects financial harm. We sought to determine how financial costs and burden relate to decisions for breast cancer surgery.

METHODS Women (≥ 18 years old) with a history of breast cancer were recruited from the Army of Women and Sisters Network to complete an 88-item electronic survey. Descriptive statistics and regression analysis were used to evaluate the impact of costs on surgical decisions and financial harm after breast cancer surgery.

RESULTS A total of 607 women with stage 0 to III breast cancer were included. Most were white (90%), were insured privately (70%) or by Medicare (25%), were college educated (78%), and reported household incomes of more than $74,000 (56%). Forty-three percent underwent breast-conserving surgery, 25% underwent mastectomy, 32% underwent bilateral mastectomy, and 36% underwent breast reconstruction. Twenty-eight percent reported that costs of treatment influenced their surgical decisions, and at incomes of $45,000 per year, costs were prioritized over breast preservation or appearance. Overall, 35% reported financial burden as a result of their cancer treatment, and 78% never discussed costs with their cancer team. When compared with breast-conserving surgery, bilateral mastectomy with or without reconstruction was significantly associated with higher incurred debt, significant to catastrophic financial burden, treatment-related financial hardship, and altered employment. Among the highest incomes, 65% of women were fiscally unprepared, reporting higher-than-expected (26%) treatment costs.

CONCLUSION Cancer treatment costs influenced decisions for breast cancer surgery, and comparably effective surgical treatments differed significantly in their risk of patient-reported financial burden, debt, and impact on employment. Cost transparency may inform preference-sensitive surgical decisions and improve patient-centered care.

J Oncol Pract 15:e666-e676.

J Oncol Pract. 2019; 15: e666-76

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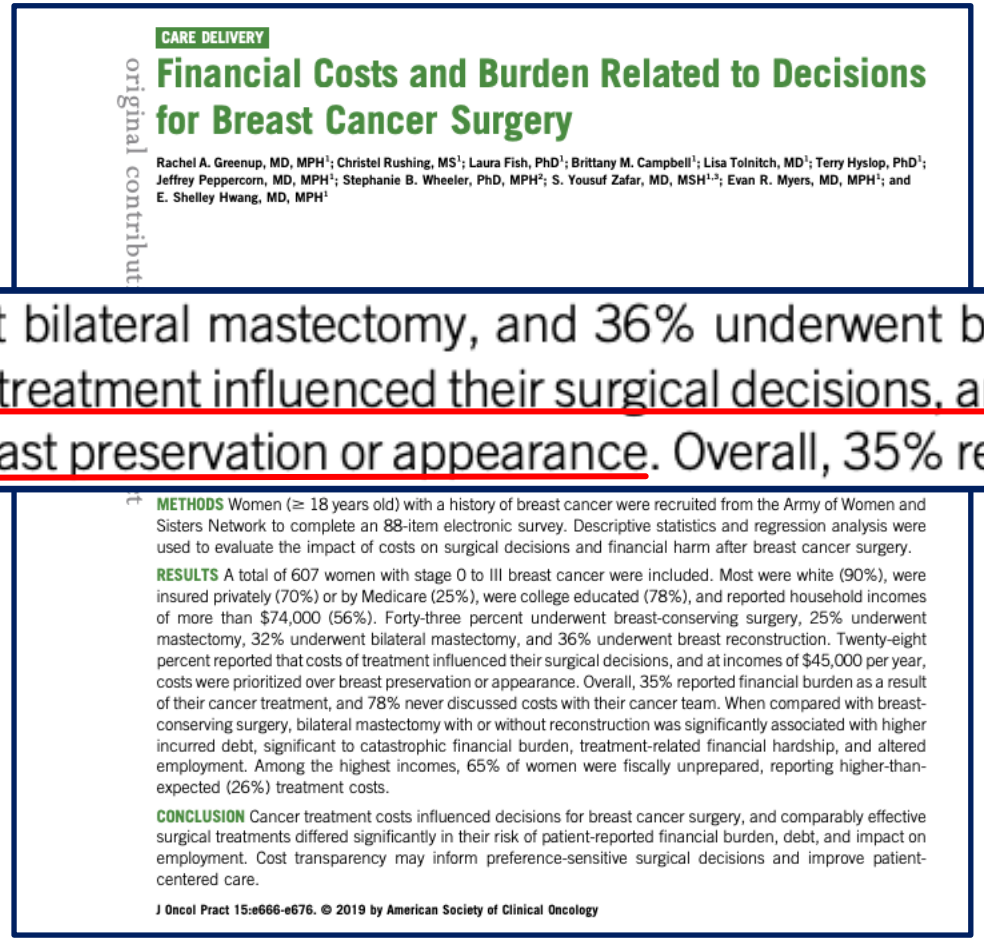
Impact of cost information in breast cancer surgery



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J Oncol Pract. 2019; 15: e666-76

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Patient attitudes on cost discussions and risk factors for FT

BREAST

Self-Reported Risk Factors for Financial Distress and Attitudes Regarding Cost Discussions in Cancer Care: A Single-Institution Cross-Sectional Pilot Study of Breast Reconstruction Recipients

Malke Asaad, M.D.
Chad Bailey, M.D.
Stefanos Boukovalas, M.D.
Jun Liu, Ph.D.
Mark W. Clemens, M.D.
Jesse Selber, M.D., M.P.H.
Charles E. Butler, M.D.
Anaeze C. Offodile II, M.D., M.P.H.

Houston, Texas; and Renton, Wash.

Background: High treatment costs associated with breast cancer are a substantial burden to patients and society. Despite mounting awareness, patient perspectives about the value of cost discussions in breast reconstruction and risk factors for financial distress are unknown.
Methods: The authors performed a single-institution, cross-sectional survey of all women who underwent breast reconstruction following mastectomy or lumpectomy for breast cancer or risk reduction. Questions were derived from previously published survey items, and the authors leveraged regression analysis to identify patient-level risk factors for major financial distress.
Results: A total of 647 of 2293 patients returned the survey questionnaires (28.2 percent response rate). From the 647 respondents, 399 (62 percent) underwent breast reconstruction, and of these, 140 (35 percent) reported that total treatment expenses were higher than expected. One hundred twenty-nine breast reconstruction patients (32 percent) paid over $5000 in out-of-pocket costs. Two hundred eighty-four (71 percent) felt that surgeons should explain the estimated out-of-pocket costs when choosing a type of breast reconstruction and 205 (51 percent) believed that a financial consultation should be scheduled with every new cancer diagnosis. However, only 52 patients (13 percent) reported having had cost discussions with the treatment team. The incidence of major financial distress was $n = 70$ (18 percent), and following regression analysis, higher credit score and annual income were associated with a 66 percent and 69 percent risk reduction, respectively.
Conclusions: Recipients of breast reconstruction demonstrate unanticipated and unplanned financial strain related to out-of-pocket expenses and believe that cost-consciousness should impact treatment decisions. Lower income and credit score are associated with financial distress. Cost discussions may optimize decision-making in preference sensitive conditions. (*Plast. Reconstr. Surg.* 147: 587e, 2021.)

Hot Topic Video

Plast Reconst Surg. 2021; 147(4): 587e-595e

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Risk factors for self-reported FT

- **Single institution 29-item patient survey**
  - Adult pts, 1/2018 – 6/2019, receipt of BR due to cancer, DCIS or BRCA+
  - Demographics, cancer expenses and experience with cancer treatment overall
  - Cross-linked with electronic record and de-identified

- Multivariate regression analysis
  - Response to prompt “what degree of financial burden have cancer treatment costs been on you or your family?

- 28.2% response rate (n = 647 patients)
  - 399 patients had BR (study focus)

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Principal findings

Table 4. Univariate and Multivariable Regression Model of Major Financial Burden Risk Factors*

	Univariate Analysis		Multivariable Analysis	
	OR (95% CI)	*p*	OR (95% CI)	*p*
Age	0.97 (0.95–0.99)	0.003		
Race (as reported by the patient)				
Caucasian/white	Ref			
Latino	2.32 (0.94–5.74)	0.075†		
African American	5.01 (2.09–11.99)	<0.001†		
Other	1.69 (0.48–6.05)	0.678†		
Income				
<$80,000	Ref		Ref	
≥$80,000	0.19 (0.11–0.33)	<0.001	0.31 (0.17–0.58)	<0.001
Marital status				
Single	Ref			
Married	0.34 (0.14–0.81)	0.013†		
Other	0.75 (0.28–2.04)	0.721†		
Insurance provider throughout the majority of breast cancer treatment				
Medicare	Ref			
Employer based	3.05 (1.05–8.86)	0.039†		
Other	2.21 (0.54–9.02)	0.333†		
Prescription drug coverage (yes vs. no)	1.86 (0.42–8.25)	0.547		
Credit score at the time of your breast cancer diagnosis				
<740	Ref		Ref	
≥740	0.23 (0.13–0.41)	<0.001	0.34 (0.19–0.63)	<0.001
Were you employed at the time of your breast cancer diagnosis (yes vs. no)	2.33 (1.22–4.44)	0.010		

Ref, reference.*Major financial distress (i.e., significant or catastrophic financial burden) was identified in 70 respondents (18 percent), whereas 323 (82 percent) reported minor financial distress (i.e., no/minor/moderate financial burden).†*p* values and 95% CIs were corrected by the Dunnett method.

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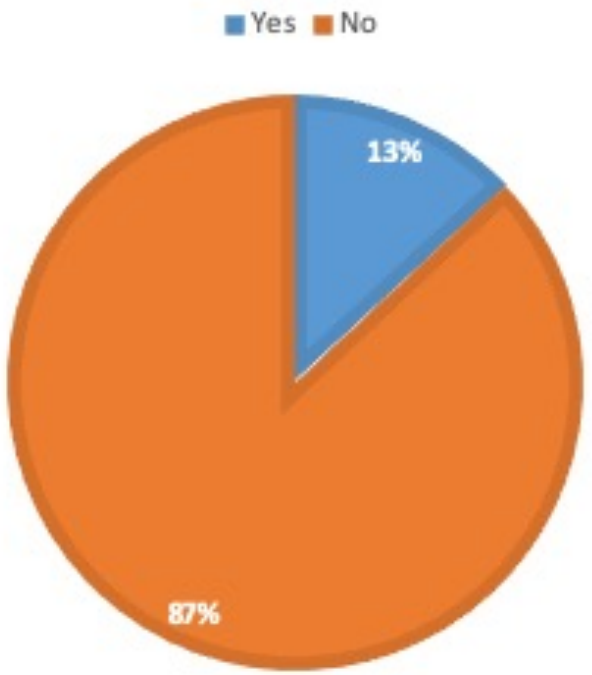
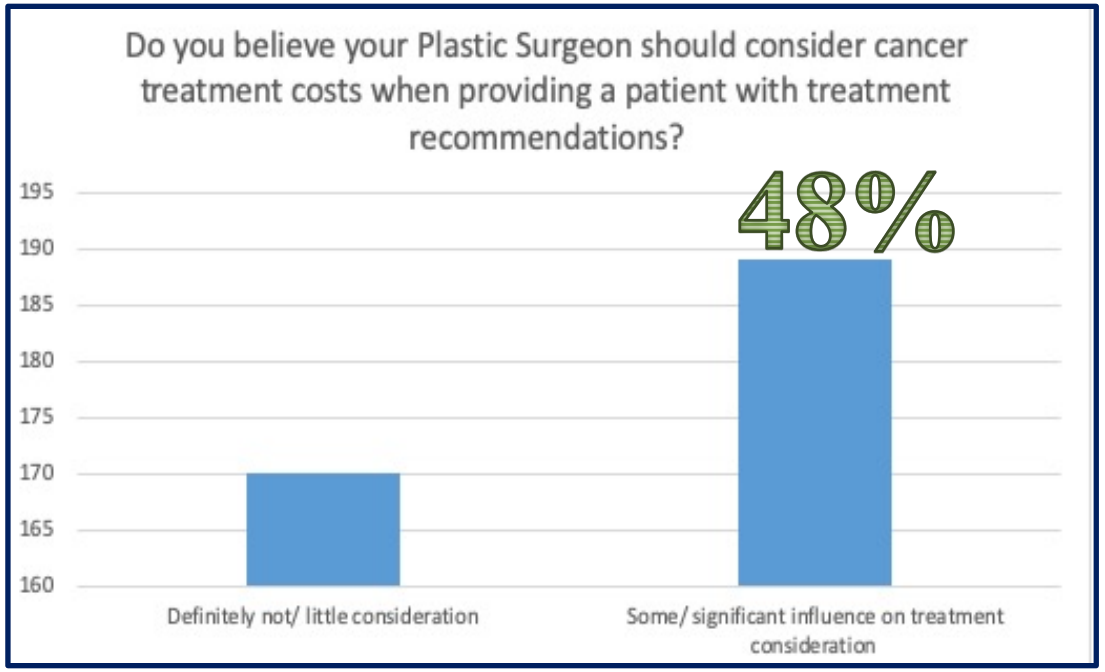
Frequency and importance of cost discussions



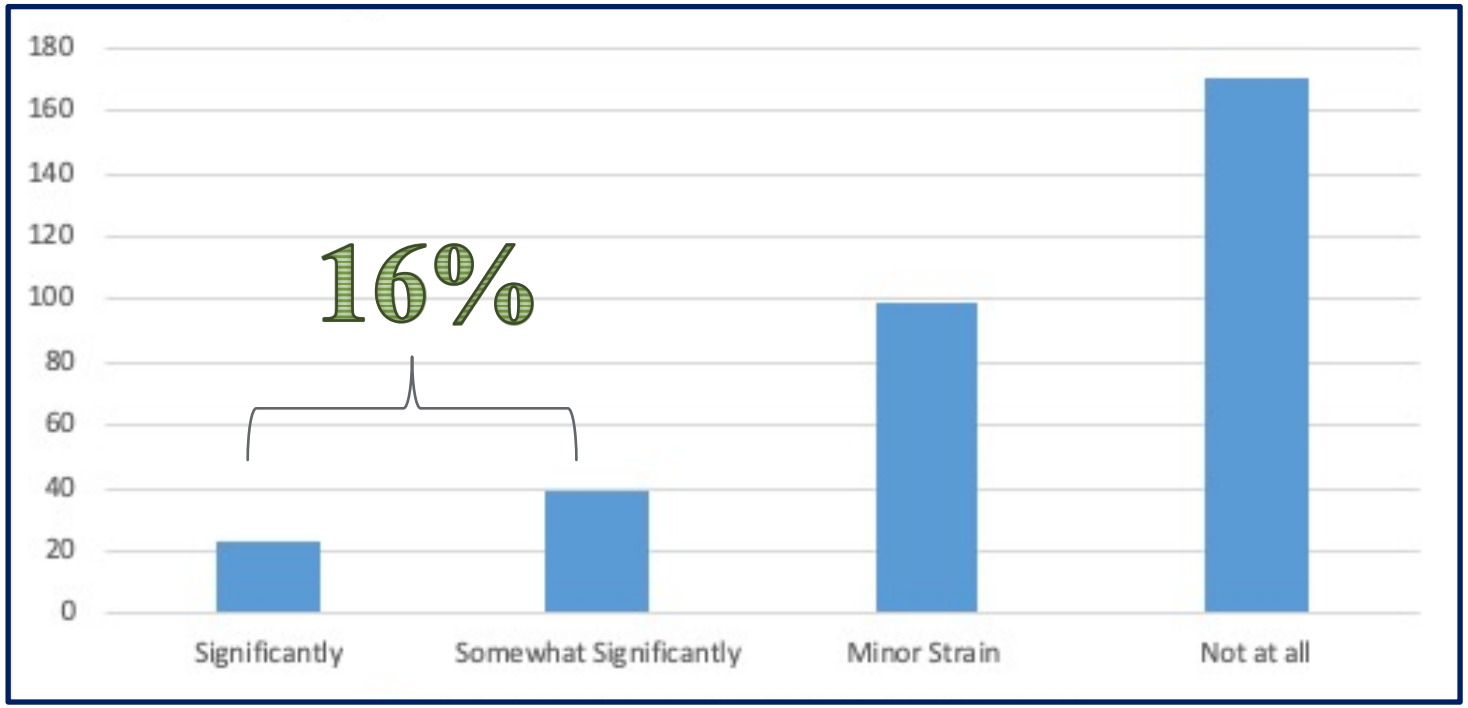
I discuss costs with my surgeon or someone on the care team



Plastic surgeons should factor costs in planning

Plast Reconst Surg. 2021; 147(4): 587e-595e

Pursuing breast reconstruction caused financial strain



Plast Reconst Surg. 2021; 147(4): 587e-595e

Similar findings in a national survey-based analysis

Ann Surg Oncol
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Annals of SURGICAL ONCOLOGY
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ORIGINAL ARTICLE – RECONSTRUCTIVE ONCOLOGY

Financial Toxicity in Breast Reconstruction: A National Survey of Women Who have Undergone Breast Reconstruction After Mastectomy

Nishant Ganesh Kumar, MD[1], Nicholas L. Berlin, MD, MPH[1,2], Sarah T. Hawley, PhD, MPH[3], Reshma Jagsi, MD, DPhil[4], and Adeyiza O. Momoh, MD[1]

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ABSTRACT

Background. Despite awareness regarding financial toxicity in breast cancer care, little is known about the financial strain associated with breast reconstruction. This study aims to describe financial toxicity and identify factors independently associated with financial toxicity for women pursuing post-mastectomy breast reconstruction.

Methods. A 33-item electronic survey was distributed to members of the Love Research Army. Women over 18 years of age and at least 1 year after post-mastectomy breast reconstruction were invited to participate. The primary outcome of interest was self-reported financial toxicity due to breast reconstruction, while secondary outcomes of interest were patient-reported out-of-pocket expenses and impact of financial toxicity on surgical decision making.

Results. In total, 922 women were included (mean age 58.6 years, standard deviation 10.3 years); 216 women (23.8%) reported financial toxicity from reconstruction. These women had significantly greater out-of-pocket medical expenses. When compared with women who did not experience financial toxicity, those who did were more likely to have debt due to reconstruction (50.9% vs. 3.2%, $p < 0.001$). Younger age, lower annual household income, greater out-of-pocket expenses, and a postoperative major complication were independently associated with an increased risk for financial toxicity. If faced with the same decision, women experiencing financial toxicity were more likely to decide against reconstruction ($p < 0.001$) compared with women not experiencing financial toxicity.

Conclusions. Nearly one in four women experienced financial toxicity from breast reconstruction. Women who reported higher levels of financial toxicity were more likely to change their decisions about surgery. Identified factors predictive of financial toxicity could guide preoperative discussions to inform decision making that mitigates undesired financial decline.

Keywords Post-mastectomy reconstruction · Breast reconstruction · Financial toxicity · Debt · Out-of-pocket expenses

Within the United States, individuals can enroll in private or public health insurance plans. Private coverage can be obtained through employment-based plans (provided through an employer), direct-purchase plans (purchased directly from an insurance company), and insurance plans for uniformed service members.[1] Public options include Medicare (for individuals aged 65 years or older), Medicaid (for low-income individuals and those with disabilities), and coverage through the Department of Veterans Affairs.[1] Individuals may incur out-of-pocket (OOP) costs in the form of co-payments (fixed dollar amount paid for healthcare services or prescriptions), deductibles (fixed dollar amount paid for healthcare

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Leveraged 922 women via the Susan Love Research Foundation

- 2% response rate (45,870 received survey)

25.8% self-reported financial toxicity following breast reconstruction

Associated with

- Increased risk of debt (51% vs. 3.2%)
- Increased out-of-pocket medical expenses
- Younger age, lower annual income, post-op complications

Considerable decision regret among patients with financial toxicity

Ann Surg Oncol. 2022; 29(1): 535-44

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Why are cost discussions so important?

Original Contribution | FOCUS ON QUALITY

ReCAP

ReCAPs (Research Contributions Abbreviated for Print) provide a structured, one-page summary of each paper highlighting the main findings and significance of the work. The full version of the article is available online at jop.ascopubs.org.

Discussing Health Care Expenses in the Oncology Clinic: Analysis of Cost Conversations in Outpatient Encounters

Wynn G. Hunter, S. Yousuf Zafar, Ashley Hesson, J. Kelly Davis, Christine Kirby, Jamison A. Barnett, and Peter A. Ubel

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Disclosures provided by the authors are available with this article at jop.ascopubs.org.

DOI: https://doi.org/10.1200/JOP.2017.022855; published online ahead of print at jop.ascopubs.org on August 23, 2017.

QUESTION ASKED: The objective of this study is to determine the frequency, duration, and content of patient-oncologist discussions about health care costs in breast cancer clinic visits.

SUMMARY ANSWER: Cost conversations occurred in 22% of visits, had a median duration of 33 seconds, and were initiated more often by oncologists than by patients. Although oncologists most frequently brought up costs of antineoplastic therapies (eg, endocrine therapies, targeted agents, and chemotherapy), patients most commonly brought up costs of diagnostic tests. Thirty-eight percent of cost conversations mentioned cost-reducing strategies, which most commonly sought to lower patient costs for endocrine therapies and symptom-alleviating treatments (eg, opioid analgesics, antiemetics). The three most commonly discussed cost-reducing strategies were: switching to a lower-cost therapy/diagnostic, changing logistics of the intervention, and facilitating copay assistance.

WHAT WE DID: We performed mixed-methods content analysis of transcribed dialogue from 677 outpatient appointments for breast cancer management. Encounters featured 677 patients with breast cancer visiting 56 oncologists nationwide from 2010 to 2013.

BIAS, CONFOUNDING FACTOR(S): The study sample limits the generalizability of our findings because it was composed entirely of breast oncology visits. Cost conversations in this setting may not be representative of those in other oncology settings. Also, we had access to only one recording per patient; accordingly, it is unknown whether cost was discussed in visits before or after the one recorded. Because earlier cost conversations may obviate the need for future ones, our analysis may have underestimated cost conversation incidence. Furthermore, although we sampled patients across a broad range of geographic regions, and assessed insurance coverage, we did not evaluate patients' incomes. Last, we did not have access to follow-up data and could not assess the impact of cost conversations on actual costs, adherence, or clinical outcomes.

REAL-LIFE IMPLICATIONS: Altogether, these data evidence the willingness and capability of oncologists and their patients to engage in cost conversations despite time pressure and price opacity. Moreover, they are aware of a wide variety of potential cost-saving solutions and mention them in more than one third of cost conversations. By illuminating categories of cost-reducing strategies and providing example quotes, we highlight potential solutions to patient cost problems that could directly inform clinical practice. JOP

Journal of Oncology Practice. 2017; 13(11): e944-956

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Why are cost discussions so important?

33 seconds

Original Contribution | FOCUS ON QUALITY

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Why are cost discussions so important?

Financial toxicity

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Journal of Oncology Practice. 2017; 13(11): e944-956

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Why is FT in the context of breast cancer surgery important?

Relationship b/w FT and quality-of-life

ORIGINAL SCIENTIFIC ARTICLE

Correlation Between Financial Toxicity, Quality of Life, and Patient Satisfaction in an Insured Population of Breast Cancer Surgical Patients: A Single-Institution Retrospective Study

Christopher J Coroneos, MD, MSc, FRCSC, Yu-Li Lin, MS, Chris Sidey-Gibbons, PhD, Malke Asaad, MD, Brian Chin, MD, MSc, Stefanos Boukovalas, MD, Margaret S Roubaud, MD, FACS, Makesha Miggins, MD, FACS, Donald P Baumann, MD, FACS, Anaeze C Offodile II, MD, MPH

BACKGROUND: The relationship between treatment-related, cost-associated distress "financial toxicity" (FT) and quality-of life (QOL) in breast cancer patients remains poorly characterized. This study leverages validated patient-reported outcomes measures (PROMs) to analyze the association between FT and QOL and satisfaction among women undergoing ablative breast cancer surgery.

STUDY DESIGN: This is a single-institution cross-sectional survey of all female breast cancer patients (>18 years old) who underwent lumpectomy or mastectomy between January 2018 and June 2019. FT was measured via the 11-item COmprehensive Score for financial Toxicity (COST) instrument. The BREAST-Q and SF-12 were used to asses condition-specific and global QOL, respectively. Responses were linked with demographic and clinical data. Pearson correlation coefficient and multivariable regression were used to examine associations.

RESULTS: Our analytical sample consisted of 532 patients; mean age 58, mostly white (76.7%), employed (63.7%), married/committed (73.7%), with 64.3% undergoing reconstruction. Median household income was $80,000 to $120,000/year, and mean COST score was 28.0. After multivariable adjustment, a positive relationship for all outcomes was noted; lower COST (greater cost-associated distress) was associated with lower BREAST-Q and SF-12 scores. This relationship was strongest for BREAST-Q psychosocial well-being, for which we observed a 0.89 (95% CI 0.76−1.03) change per unit change in COST score.

CONCLUSIONS: Financial toxicity captured in this study correlates with statistically significant and clinically important differences in BREAST-Q psychosocial well-being, patient satisfaction with reconstructed breasts, and SF-12 global mental and physical quality of life. Treatment costs should be included in the shared decision-making for breast cancer surgery. Future prospective outcomes research should integrate COST. (J Am Coll Surg 2020;■:1−11. © 2020 by the American College of Surgeons. Published by Elsevier Inc. All rights reserved.)

J Am Coll Surg. 2021; 232(3): 253-63

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Relationship b/w FT and quality-of-life

- **Correlation between FT (COST score) and QOL**
  - Condition-specific: Breast-Q (One QoL & Two patient satisfaction domains)
  - Global: SF-12 (mental & physical)
  - Cross-sectional analysis of overall population and BR patients

- **Multivariate regression model to examine association**
  - Pre-specified cut-offs for correlation coefficients

- **Sensitivity analysis**
  - Mastectomy only and pts with > 1 yr follow-up

FT and PRO (all patients)

r = 0.54

r = 0.19

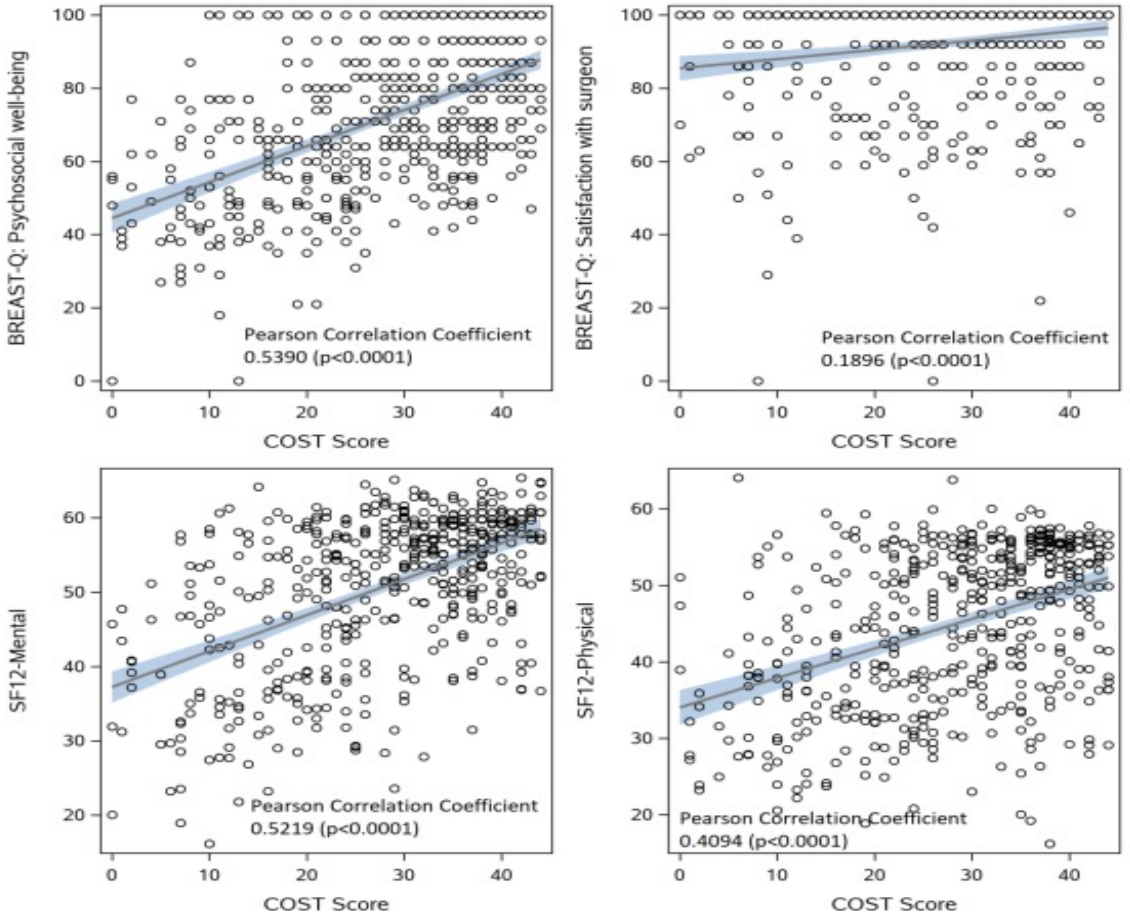


Figure 1. Relationship between COST score and patient-reported satisfaction and life quality measures in the entire cohort. The linear regression line and its 95% confidence limits are also shown in each graph.

r = 0.52

r = 0.41

FT and PRO (BR patients)

r = 0.48

r = 0.25

r = 0.13

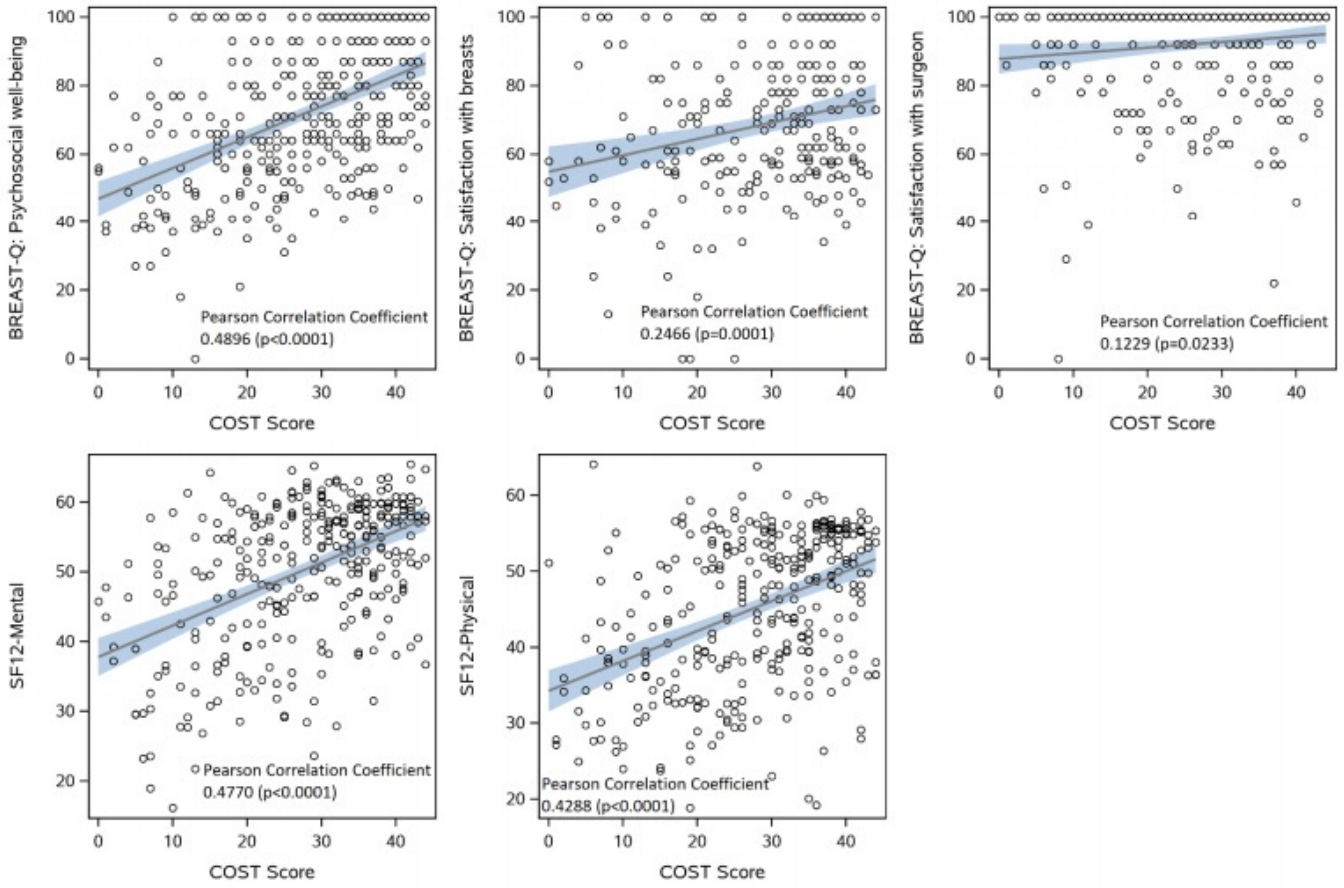


Figure 2. Relationship between COST score and patient-reported satisfaction and life quality measures in the reconstruction sub-cohort. The linear regression line and its 95% confidence limits are also shown in each graph.

r = 0.48

r = 0.43

Changes in PRO scores per unit change in COST score

Satisfaction/life quality measure	Patients, n	Mean ± SD	Change in PROM (95% CI) per unit of COST score	
			Unadjusted	Adjusted
Entire cohort				
BREAST-Q: psychosocial wellbeing*	526	72.1 ± 20.3	0.99 (0.86–1.12)	0.89 (0.76–1.03)†
BREAST-Q: satisfaction with surgeon‡	531	92.5 ± 14.6	0.25 (0.14–0.36)	0.20 (0.09–0.31)†
SF12-Physical§	495	44.8 ± 10.3	0.38 (0.31–0.46)	0.32 (0.24–0.40)†
SF12-Mental‖	495	50.7 ± 10.2	0.49 (0.42–0.56)	0.45 (0.38–0.52)†

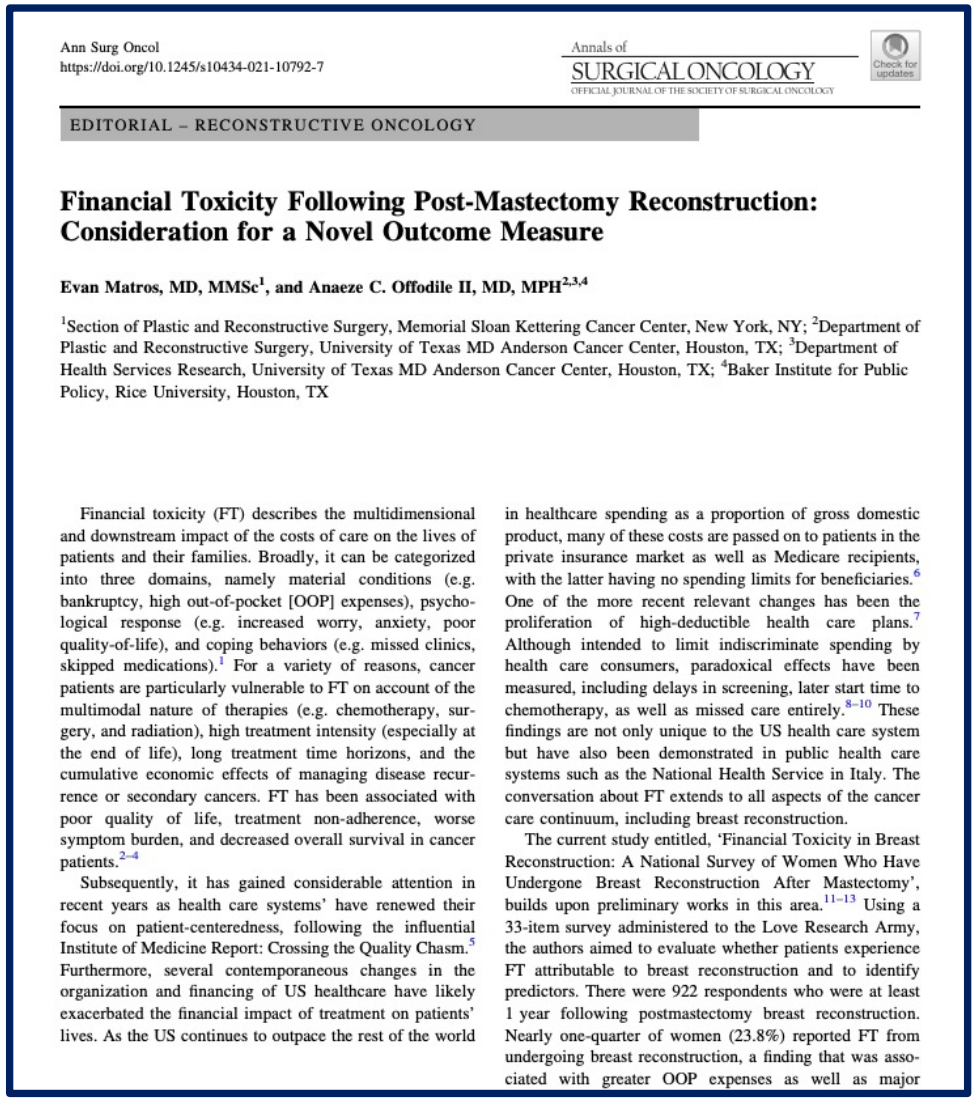
J Am Coll Surg. 2021; 232(3): 253-63

Changes in PRO scores per unit change in COST score

Satisfaction/life quality measure	Patients, n	Mean ± SD	Change in PROM (95% CI) per unit of COST score	
			Unadjusted	Adjusted
Reconstruction sub-cohort				
BREAST-Q: psychosocial wellbeing[¶]	340	72.0 ± 20.1	0.90 (0.73–1.07)	0.80 (0.63–0.97)[†]
BREAST-Q: satisfaction with surgeon[#]	341	92.3 ± 14.5	0.16 (0.02–0.31)	0.13 (-0.01–0.28)
BREAST-Q: satisfaction with breasts[**]	234	68.4 ± 20.9	0.50 (0.26–0.75)	0.41 (0.17–0.65)[†]
SF12-Physical[††]	318	45.2 ± 10.0	0.39 (0.30–0.48)	0.32 (0.23–0.41)[†]
SF12-Mental[‡‡]	318	50.2 ± 10.3	0.45 (0.36–0.55)	0.37 (0.27–0.46)[†]

J Am Coll Surg. 2021; 232(3): 253-63

FT as a marker of surgical care quality?



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Annals of SURGICAL ONCOLOGY
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EDITORIAL – RECONSTRUCTIVE ONCOLOGY

Financial Toxicity Following Post-Mastectomy Reconstruction: Consideration for a Novel Outcome Measure

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Financial toxicity (FT) describes the multidimensional and downstream impact of the costs of care on the lives of patients and their families. Broadly, it can be categorized into three domains, namely material conditions (e.g. bankruptcy, high out-of-pocket [OOP] expenses), psychological response (e.g. increased worry, anxiety, poor quality-of-life), and coping behaviors (e.g. missed clinics, skipped medications).[1] For a variety of reasons, cancer patients are particularly vulnerable to FT on account of the multimodal nature of therapies (e.g. chemotherapy, surgery, and radiation), high treatment intensity (especially at the end of life), long treatment time horizons, and the cumulative economic effects of managing disease recurrence or secondary cancers. FT has been associated with poor quality of life, treatment non-adherence, worse symptom burden, and decreased overall survival in cancer patients.[2–4]

Subsequently, it has gained considerable attention in recent years as health care systems' have renewed their focus on patient-centeredness, following the influential Institute of Medicine Report: Crossing the Quality Chasm.[5] Furthermore, several contemporaneous changes in the organization and financing of US healthcare have likely exacerbated the financial impact of treatment on patients' lives. As the US continues to outpace the rest of the world in healthcare spending as a proportion of gross domestic product, many of these costs are passed on to patients in the private insurance market as well as Medicare recipients, with the latter having no spending limits for beneficiaries.[6] One of the more recent relevant changes has been the proliferation of high-deductible health care plans.[7] Although intended to limit indiscriminate spending by health care consumers, paradoxical effects have been measured, including delays in screening, later start time to chemotherapy, as well as missed care entirely.[8–10] These findings are not only unique to the US health care system but have also been demonstrated in public health care systems such as the National Health Service in Italy. The conversation about FT extends to all aspects of the cancer care continuum, including breast reconstruction.

The current study entitled, 'Financial Toxicity in Breast Reconstruction: A National Survey of Women Who Have Undergone Breast Reconstruction After Mastectomy', builds upon preliminary works in this area.[11–13] Using a 33-item survey administered to the Love Research Army, the authors aimed to evaluate whether patients experience FT attributable to breast reconstruction and to identify predictors. There were 922 respondents who were at least 1 year following postmastectomy breast reconstruction. Nearly one-quarter of women (23.8%) reported FT from undergoing breast reconstruction, a finding that was associated with greater OOP expenses as well as major

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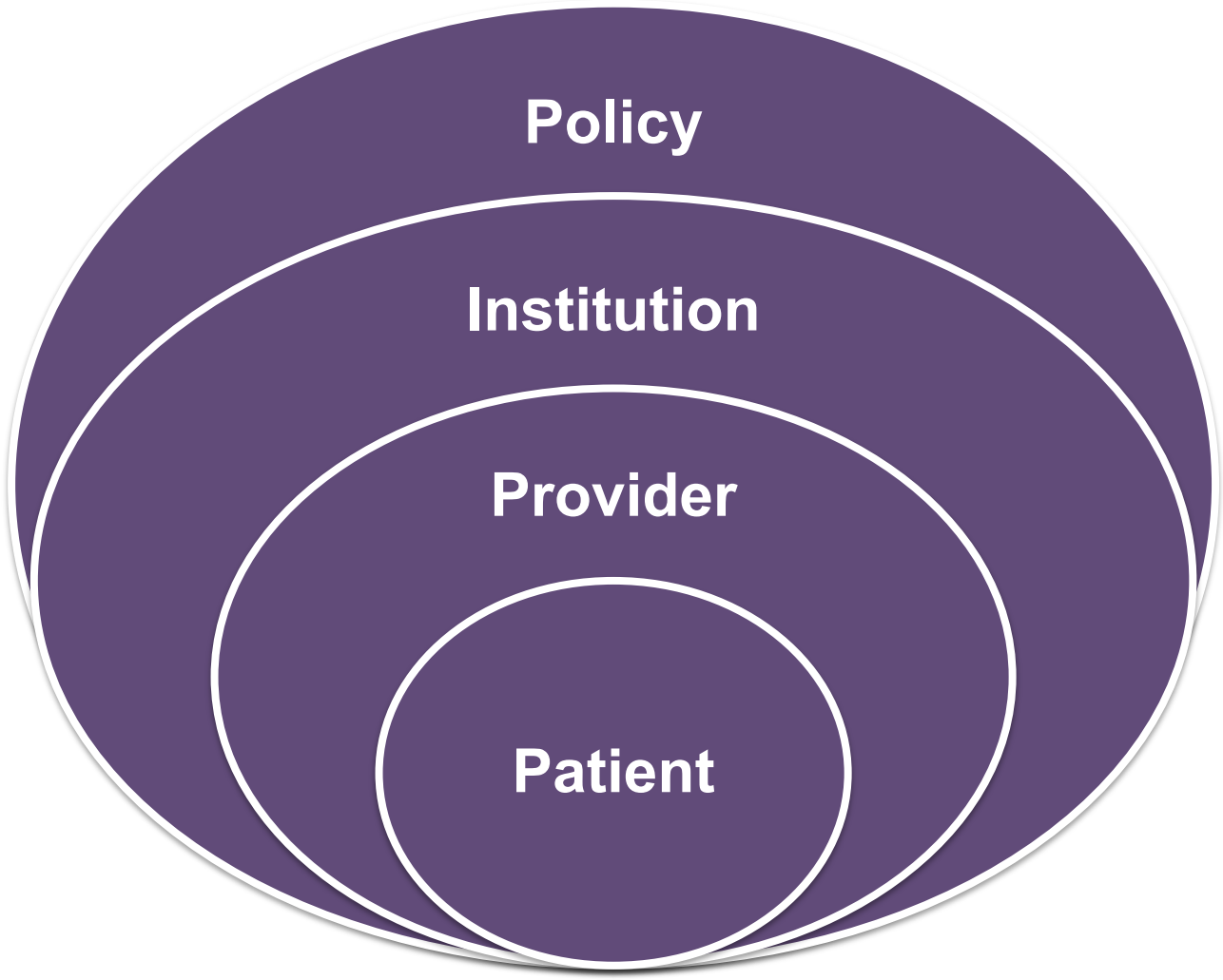
Difficult problem = multi-level solutions



Solutions must exist within reinforcing systemic, institutional, and interpersonal frameworks

Difficult problem = multi-level solutions

VIEWPOINT

A Coordinated Policy Approach to Address Medical Financial Toxicity

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Financial toxicity following cancer treatment is increasingly prevalent. Evidence suggests that few families can afford unexpected expenses exceeding $400, and even small increases in out-of-pocket costs are associated with treatment nonadherence,[1] potentially widening nationally recognized societal disparities in cancer treatment and survival. High costs may render cancer care unaffordable for the individual patient who is uninsured or underinsured. Despite growing economic and health gaps, a coordinated nationwide policy approach, one that supports clinicians and patients, to curbing cancer's (as well as other conditions') financial burden is lacking.

Clinicians' Role

Current approaches to addressing financial toxicity call for clinician practice change. The authors of this Viewpoint have advocated for the development of financial hardship screening tools as quality measures implemented at the practice level as part of high-quality care delivery.[2] The Oncology Care Model sponsored by the Center for Medicare and Medicaid Innovation requires that participating practices have the core functions of navigation, including connecting patients and caregivers to resources.[3] Widespread adoption of patient navigators in medical practices is nonetheless hindered by the lack of a sustained financial model for reimbursement, despite research that supports their value.[4]

Some researchers advocate for incorporating cost discussions into shared treatment decisions and making treatment costs transparent, aiding patients in making informed choices. However, costs, especially out-of-pocket costs, are rarely transparent, and benefits are difficult to quantify for a given patient, disease, and clinician.[5] One must also question the benefit of these conversations to patients who cannot afford even the lowest tier of care. In addition, cost of care is often dependent on the ability to remain employed, and insured, while undergoing treatment. Today, few practices integrate discussions of expected costs and other economic outcomes into shared treatment decision-making.

Support for Clinicians

Without practice-based support and reimbursement it may be too much to ask health care professionals, particularly those who are community based or who treat a greater proportion of low-income or uninsured patients, to shoulder the responsibility for financial toxicity screening and services to mitigate toxicity. Survivorship care plans, for example, were widely endorsed by professional organizations, researchers, and some health care professionals, but were never fully adopted owing, in part, to clinician concerns regarding insufficient time and personnel for completion, lack of reimbursement, and magnitude of benefit. Practice-based approaches to alleviating the financial hardship associated with cancer treatment may face similar barriers despite convincing evidence that services such as financial navigation are effective at reducing burden for patients and their families. Moreover, practice-based approaches may face an additional barrier owing to the inherent conflict of interest driven by higher revenues from high-cost drugs under the "buy and bill" payment model, which is common in oncology[6] practice.

Some practice-level financial screening and mitigation as part of routine care, as well as reimbursement for these activities and technical support for effective approaches are appropriate despite the potential barriers. Financial navigators, for example, may assume the responsibility to connect patients to resources, beyond assuring that the clinician is reimbursed. The development and use of decision support tools to incorporate treatment cost, harm-benefit tradeoffs, and value in the shared decision-making discussion may also be helpful. Data that track social determinants of health alongside financial services and their outcomes may support the justification for these activities and inform when and where to apply modifications. Funding and reimbursement for these roles and responsibilities, if implemented, are necessary for them to succeed and be sustained.

Need for Policy

A coordinated national policy approach, one that joins and supports practice-based efforts, to alleviate cancer's financial toxicity is imperative. Although much legislative attention focuses on curbing pharmaceutical drug prices, several other critical policies, including those related to insurance coverage options outside of employment, flexible work schedule, paid sick leave, financial planning assistance, and limits on out-of-pocket spending relative to household income and assets, are helpful to reduce financial burden for patients and their families during cancer treatment. Policies that offer protection from high out-of-pocket costs are actionable steps that should have bipartisan support. Fee-for-service Medicare beneficiaries, many of whom live on fixed incomes, face coinsurance for medical services and prescription drugs without any annual out-of-pocket cap. Private high-deductible health plans are increasingly common, with annual maximums that exceed what many families can afford and often not applicable to out-of-network care. In addition, patients and families with very low incomes may find that the cost of cancer care

JAMA Oncol. 2021; 7(12): 1761-1762

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Financial navigation = ? panacea

comments and controversies

Financial Navigation in Cancer Care Delivery: State of the Evidence, Opportunities for Research, and Future Directions

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Background

Financial toxicity (FT) describes the significant economic burden imposed by cancer treatment on American households.[1] In recent years, the incidence and severity of FT have regrettably escalated because of the high cost structure (direct and indirect) associated with cancer diagnosis, treatment, and survivorship. This reality has heightened attention, across the broad health care stakeholder community, to finding solutions to FT at the policy, payer, and health system levels. Financial navigation (FN) is increasingly recognized as a health system–level intervention with the potential to significantly mitigate the onset, severity, and duration of FT.[2] It denotes the provision of individualized assistance to patients, families, and caregivers to overcome the financial barriers to timely, high-quality care such as high copayments, difficulty in finding the optimal health plan, and high nonmedical costs associated with care such as transportation, lodging, and meals.[3] In addition to the more traditional role of connecting patients to financial assistance resources, FN also involves helping patients understand the financial aspects of their care, budget appropriately, and manage their employment and disability benefits in the context of ongoing financial commitments as they navigate the cancer care continuum. Recent studies suggest that connecting patients and caregivers with FN services is feasible, leads to reductions in patients' anxiety about costs, and provides concrete assistance with medical and nonmedical costs. In a recent pilot study, for example, patients with cancer and caregivers from low-income households received significant assistance with cost of living expenses (eg, food and rent) through community-based FN organizations.[4,5] In another study, hospital-hired trained oncology financial navigators saved patients and hospital systems $39,000,000 US dollars critical in not only mitigating FT but also decreasing the likelihood that patients will consider harmful trade-offs like forgoing needed care because of costs.

In this article, we discuss the current state of oncology FN in the United States, highlight the various approaches to deliver these services, and discuss enduring research questions.

Current Landscape of Financial Navigation

Foundations and other community-based organizations have long been resources for financial assistance and navigation to patients and families who request their services. Unfortunately, many patients who would benefit from such services may never access these organizations for a variety of reasons including overwhelming and limited knowledge. Given the high prevalence of FT, expecting patients to self-identify financial assistance may lead to inequity in access and outcomes; oncology clinics need to be able to readily and equitably identify patients at risk and provide FN proactively. Unfortunately, recent studies highlight significant room for improvement in our ability to effectively screen and connect patients with cancer to FN. A survey of community oncology practices revealed that < 50% of practices routinely provide financial counselors or proactively engage patients to discuss treatment costs.[7] In addition, a National Cancer Institute survey of FN services at US Comprehensive Cancer Centers revealed a lack of cost transparency, an inability to predict patient costs, and a general reluctance by oncologists to engage in cost conversations.[8] The latter is salient as both the National Academy of Medicine and ASCO have strongly advocated for integrating cost conversations into routine practice.[9,10] In the same survey, most centers reported being able to identify patients at high risk for

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What can we do?

Mitigation Strategy	Examples
Cost discussions and financial literacy	Education of care providers and patients about resources. Cost discussions by any/all care team members
Screening tools	Integrate COST tool into clinic workflow. Identify patients who might benefit from targeted referrals
De-emphasize low-value care	Avoid routine pre-op testing in low-risk clinical situations e.g. fat grafting
Change the care plan	Switch to generic Rx, consolidate post-op visits with other providers to limit travel burden
Implement financial navigation	Direct patients to resources e.g. switching plans, co-pay assistance

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Online patient resources for financial toxicity

https://medicineassistancetool.org/
PhRMA's Medicine Assistance Tool is a search engine designed to help patients, caregivers and healthcare providers learn more about resources available through the various biopharmaceutical industry programs.
http://www.benefits.gov/
The official benefits website of the US government, designed to help users find government benefit and assistance programs for which they may be eligible.
http://www.cancer.org/
The Cancer Helpline, available 24 hours a day, connects callers with trained staff who can answer general questions about cancer, provide information on support services, and offer help in finding financial assistance programs and services locally and throughout the USA.
http://www.cancerfac.org/
The Cancer Financial Assistance Coalition is a coalition of organizations that help patients with cancer manage their financial challenges by educating them about existing resources.
http://www.cancercare.org/
CancerCare provides free professional support services and information to help anyone affected by cancer. Services include individual and group counseling, support groups, educational workshops, publications, practical help and referrals.
http://www.cancercarecopay.org/
The CancerCare Co-Payment Assistance Foundation is a nonprofit organization dedicated to helping qualified patients afford co-payments, coinsurance and deductibles for prescribed cancer treatments.
http://www.insurekidsnow.gov/
The Children's Health Insurance Program is a state and federal partnership that provides free or low-cost health coverage for children 18 years of age and younger whose families earn too much income to qualify for Medicaid but cannot afford to purchase private health-insurance coverage.
http://www.mygooddays.org/
Good Days provides financial support for qualified patients with chronic and life-altering diseases (including some types of cancer), which allows them access to treatment.
http://www.healthcare.gov/
The first US Department of Health and Human Services central database of health-coverage options, combining information about public programs with information from more than 1,000 private insurance plans.
http://www.healthwellfoundation.org/
This site provides full or partial financial assistance to eligible people who cannot afford prescription copayments, health-insurance premiums, deductibles and co-insurance, pediatric treatment costs and travel expenses.
http://www.lls.org/copay
The Leukemia and Lymphoma Society's Co-Pay Assistance Program offers financial assistance to patients in meeting their private insurance or Medicare premiums, and co-pays for prescription medication and allowable treatment costs.
http://www.cdc.gov/cancer/nbccedp
The Centers for Disease Control and Prevention's National Breast and Cervical Cancer Early Detection Program provides low-income, uninsured and underserved women access to screening and diagnostic services for breast and cervical cancer.
http://www.thenccs.org/
The National Children's Cancer Society provides emotional, financial and educational support to children with cancer and their families and survivors.
http://www.needymeds.org/
NeedyMeds is an online information resource dedicated to helping people who cannot afford medications and other healthcare costs.
http://www.copays.org/
The Patient Advocate Foundation's Co-Pay Relief Program provides direct financial assistance with co-payments, co-insurance and deductibles required by the patient's insurer for medications prescribed to treat and manage their disease.
http://www.thesamfund.org/
The Samfund provides support for young adult cancer survivors in the USA as they recover from the financial impact of cancer treatment.
http://www.sistersnetworkinc.org/
The Sisters Network program provides financial assistance for mammograms, co-pays, office visits, prescriptions and medical-care-related lodging and transportation.
http://www.uhccf.org/
The UnitedHealthcare Children's Foundation is dedicated to improving access to medical-care-related services for children who have medical needs that are not fully covered by their insurance.

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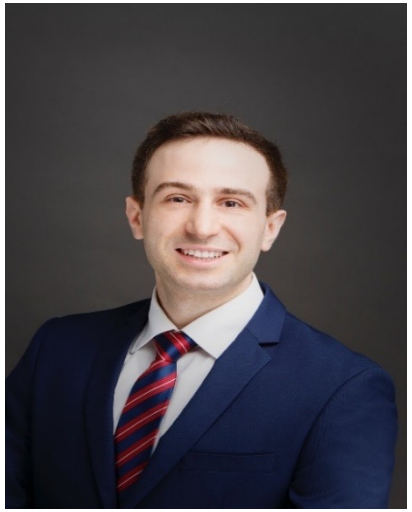

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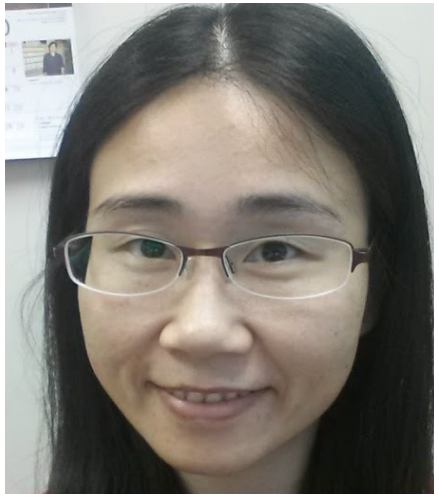

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